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Pain in people with dementia

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This chapter summarizes and discusses the main findings of this thesis. It also addresses the most important methodological issues and implications for clinical practice. Finally, the implications for further research are discussed.

Summary of the main findings

Review studies

We performed two systematic reviews (chapters 2 and 3). The first systematic review (chapter 2) reports on pain experience in dementia subtypes. We identified twelve studies that addressed pain experience in dementia subtypes. For Alzheimer's Dementia (AD), studies on clinical pain indicated a reduced pain experience compared to controls without dementia, whereas the findings of experimental studies were inconsistent. For vascular dementia (VaD), clinical studies found that primary caregivers rated pain is equal to rating of pain by primary caregivers in controls without dementia, although primary caregivers reported more painful locations in people with VaD. During self-report, people with VaD reported higher pain levels than controls without dementia. For frontotemporal dementia (FTD), experimental studies found a reduced pain experience compared to controls without dementia. We found no studies on pain experience in dementia with Lewy bodies (DLB).

The second systematic review (chapter 3) reports the prevalence of pain in dementia subtypes. The number of studies reporting the prevalence of pain per dementia subtype was limited to ten studies, and these studies showed no significant difference in prevalence of pain between the dementia subtypes. This review confirms that pain is frequently reported in people with dementia, and shows that the majority of people with dementia do not suffer from high pain intensities.

Clinical studies

In the clinical section of this thesis, chapter 5 reports the results from an observational cross-sectional cohort study in nursing home residents in the Netherlands. We included 199 nursing home residents with dementia living at dementia special care units of 10 nursing homes. We collected data on presence of pain (by observation: MOBID-2 Pain Scale and PAINAD, and by self-report

scales), pain type, pain medication, dementia subtypes, dementia severity and demographic features. We found that the prevalence of observed pain was 43% (95% CI = 36-50%) using the MOBID-2 Pain Scale. Half of the nursing home residents with observed pain had mild pain. Pain assessment with the MOBID-2 Pain Scale showed no difference in pain between dementia subtypes, but residents with more severe dementia experienced pain more often than those with less severe dementia (27% vs. 15%). About one third of the nursing home residents with observed pain suffered from moderate to severe pain, despite treatment with regularly scheduled analgesics. The prevalence of self-reported pain was significantly higher in nursing home residents with VaD (53%) compared to those with AD (18%) and other dementia subtypes (14%). Nociceptive pain was the predominant type of pain (70%), followed by mixed pain (neuropathic and nociceptive pain) (25%). Acetaminophen (paracetamol) was the most commonly prescribed analgesic (80%).

The nursing home residents with observed pain, as assessed with the MOBID-2 Pain Scale, were included in a small prospective exploratory study (chapter 6). Following the pain assessment, we communicated who of participating nursing home residents were identified as being in pain to the attending physician. We also included a non-binding treatment recommendation based on the Dutch guideline "Recognition and management of chronic pain in vulnerable elderly" (Verenso)¹. After three months, reassessment of pain took place and we found that the pain intensity was significantly reduced ($p < 0.001$). The proportion of nursing residents with persistent pain was 58%. The use of analgesic drugs did not change.

Furthermore, we collected data concerning quality of life and the presence of neuropsychiatric symptoms in the participating nursing home residents (chapter 7). Both pain and neuropsychiatric symptoms have been associated with quality of life in people with dementia, but there were no studies investigating the relation between quality of life and neuropsychiatric symptoms together with pain. We analyzed the relationship between pain, neuropsychiatric symptoms and quality of life using regression models. We found that there was no independent relationship between pain and quality of life. However, neuropsychiatric symptoms, in particular agitation and depression, were significantly associated with a lower quality of life.